

'A bed in the middle of nowhere': parents' meanings of place of death for adults with cystic fibrosis

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Abstract

As populations age and chronic conditions become more prevalent, an individual's ability to choose the location of their end-of-life care and death is increasingly considered important in the provision of good healthcare, with home implied as the ‘best’ place of death through UK government policy and specialist and voluntary palliative care services. However, considering meanings of place of end-of-life care and death is complex for young adults with life-limiting conditions where the disease course is variable and uncertain, and aggressive and palliative treatments are administered both at home and in hospital often until death. Although ‘place’ is a pivotal element in healthcare practice, research and policy, there has been little attempt to understand the meaning and importance of place in understanding experiences of care at end of life. Through analysis of in-depth interviews and letters received from parents of 27 young adults in England, Scotland and Wales who died from cystic fibrosis from 1999 to 2002 aged 17–36 years, key factors that influence families' meanings of place at end of life are presented. Both home and hospital deaths are reported, with no deaths in hospices. Preferences for possible locations of death are generally limited early in the disease course by choice of aggressive treatment, particularly lung transplantation. Rate of health decline, organisation and delivery of services, and relationships with specialist and general healthcare staff strongly influence parents' experience of death at home or in hospital, although no physical location was regarded a ‘better’ place of death. Meanings of, and attachment to place are mediated for families through these factors, questioning the appropriateness of a ‘home is best’ policy for those dying from life-limiting conditions.

Introduction

The bulk of treatment and care for those with chronic illness in Western societies is increasingly taking place in the home, fuelled by social and economic pressures (Cartier, 2003 and Martin et al., 2005) and the ability to move medical and assistive technologies into the home setting (Exley and Allen, 2007 and Poland et al., 2005). Advantages of the home environment for individuals include autonomy, control, security, privacy, and relaxation (e.g. Downing, 2008, Dyck et al., 2005 and Poland et al., 2005), features not regularly associated with a public hospital environment. The value of home care is influenced by interactions with family members giving care and being surrounded by comforts such as cherished artifacts, memories, and established routines (Exley and Allen, 2007 and Gott et al., 2004), although less idealistic home environments also exist, such as those in unsafe neighbourhoods (Downing, 2008), or lived in isolation.

As populations age and chronic conditions become more prevalent, an individual's ability to choose the location of their end-of-life care and death is increasingly considered an important factor in the provision of good healthcare and promoted in UK government policy (Department of Health, 2006 and Department of Health, 2008). This is often achieved through care pathways predicated on identifying an end-of-life stage, and encouraging professionals to initiate discussion of care preferences (Department of Health, 2008). However, a range of factors influences ability to choose place of death, including physical characteristics of disease, service availability (Grande, Addington-Hall, & Todd, 1998), access to specialist equipment (Karlsen & Addington-Hall, 1998), and informal carer support (Gomes & Higginson, 2006). The notion in recent policy that home is the 'best' location for a 'good' death (Department of Health, 2006) is further advocated in specialist and voluntary palliative care services, primarily for those with cancer (e.g. Grande et al., 1998 and Marie Curie Cancer Care, 2004). Here the benefits of home care for those with chronic conditions are echoed through a home death suggested to allow individuals a greater sense of control over their

environment and maintenance of privacy and a sense of normality (Gott et al., 2004). However, an immediate stated preference for home-based care at end of life may become moderated following reflection and discussion, for example appreciation that better care quality may be found in a hospital setting (Seymour, Payne, Chapman, & Holloway, 2007); preferences being variously influenced by social, interpersonal and pragmatic considerations (Morris, 2005 cited in Seymour et al., 2007).

Concepts of 'place' are complex and contested, being informed by disciplines including sociology and health geography. Broadly, place is an abstract concept of space 'transformed and given cultural meaning by human activity' (Cartier, 2003:2291). Although closely intertwined, three forms of place from which people give and take meaning can be observed: the physical or built environment that is developed over time; the social environment, in terms of how places are structured, organised and used; and the psychological environment, in terms of meanings of place across the lifecourse (Martin et al., 2005 and Peace et al., 2007). Places therefore bring people together, who subsequently become engaged with or estranged from their environment through bonding, associating meanings, and accumulated biographical experiences and events (Gieryn, 2000 and Peace et al., 2007).

Although 'place' is a pivotal element in healthcare practice, research and policy, there has been little attempt to understand the meanings, significance and importance of aspects of place in understanding experiences of care (Poland et al., 2005) or the social and symbolic aspects of places such as home and hospital (Martin et al., 2005). In the context of end-of-life care, greater investigation is needed of whether home really is the 'best' place of care, with reasons behind stated preferences requiring a much fuller understanding (Thomas, Morris, & Clark, 2004).

Cystic fibrosis (CF) is a multi-systemic condition, particularly affecting the lungs, whereby thick, sticky secretions lead to a cycle of lung infection and inflammation, reducing lung capacity over the

lifespan (Davies, Alton, & Bush, 2007). Three decades ago the majority of those affected did not survive childhood, yet now fuller understanding of the disease and development of more effective and aggressive treatments has dramatically improved life expectancy, such that median survival age of over 50 years is predicted for those born with CF in 2000 (Dodge, Lewis, Stanton, & Wilsher, 2007).

Current treatment and care for CF is complex, with preventative, restorative and palliative treatments administered in tandem throughout the lifecourse (Robinson, 2000). Routine treatments such as physiotherapy and intravenous antibiotics are carried out in the home, where young adults are most often assisted in their care by family members (Lowton, 2002 and McGuffie et al., 2008). As young people age and health declines, individuals become more dependent on aggressive or invasive procedures for survival. For example, non-invasive ventilation is used to manage acute respiratory failure in those awaiting lung transplantation (Madden et al., 2002), currently the last treatment option available. The vast majority of the CF population dies from respiratory failure, although the uncertain and unpredictable disease course makes predicting the precise time and nature of death, and therefore planning palliative care, difficult (Robinson, 2000).

Although thoughts of a likely early death will have a significant psychosocial impact on families (Kurland & Orenstein, 2001), only a small body of research has been conducted on where those with CF die, as the community's focus understandably lies on improving survival (Robinson, 2000). A hospital record review of 44 North American patients aged 6–46 who died between 1984 and 1993 found that only one patient died at home under hospice care, the remainder dying in hospital, with 43/44 families present at death (Robinson, Ravilly, Berde, & Wohl, 1997). Similarly, a survey of 17 CF centres in the UK and Ireland over an eight year period found that only 4% of 378 deaths had occurred at home (Cottrell, 1991). More recent reviews of hospital records indicate that over two

thirds of patients with CF die in hospital (Dellon et al., 2007 and Mitchell et al., 2000), reflecting both the proportion of patients receiving aggressive treatment at time of death and professionals' uncertainty over identifying the 'final illness' (Robinson, 2000).

Use of mechanical ventilation and lung transplantation, first attempted for those with CF in the late 1980s, has led to a higher proportion of hospital deaths occurring within the intensive care unit (ITU), with those waiting for, or having received, lung transplant more likely to be intubated at or shortly before time of death and likely to die quickly after ventilatory support is withdrawn (Dellon et al., 2007 and Ford and Flume, 2007). Although clinical outcomes of patients with CF admitted to ITU have much improved over the last two decades, under half of those currently admitted survive to hospital discharge (Vedam, Moriarty, Torzillo, McWilliam, & Bye, 2004). Furthermore, around half those who opt for transplant die while waiting for donor organs; half of those who do undergo transplant will not survive five years (Ford & Flume, 2007).

Aggressive interventions being delivered in hospital environments until the point of death (Dellon et al., 2007 and Mitchell et al., 2000) allow little clear transition from therapeutic care to a traditional model of palliative care. Few unambiguous signals can therefore be given to families that end-stage CF has been reached (Robinson, 2000) and that place of death should be considered. Furthermore, it is not known whether young people are at increased risk of receiving unwanted treatment and feeling more unsatisfied with end-of-life care than those dying at home (Dellon et al., 2007).

Other than reliance on mechanical ventilation, suggested reasons for the minority of home deaths in this population include specialist centre staff having little experience of patients dying at home, thus little knowledge of community support available, and that patients with CF, through their long involvement with the centre, might feel more secure amongst a familiar healthcare team (Robinson,

2000). Although the shift towards routine CF care performed in the home mirrors the emphasis on home care for those with other chronic conditions, whether those with CF die in hospital locations due to preference or lack of alternative options (Dellon et al., 2007), and how families experience and interpret place of end-of-life care and death, is not known. The aim of this paper is to present factors that influence and provide meanings of place of end-of-life care and death in terms of engagement with, and estrangement from, the built, social and psychological environment for bereaved parents of adults with CF.

Methods

In order to comply with the UK Data Protection Act 1998, letters about the project were sent nationally in September 2003 by the CF Trust to 275 families that it was aware had experienced the loss of a relative in the years 1999–2002. This timeframe was chosen to minimise the risk of contacting relatively newly bereaved respondents, whilst attempting to maintain currency of their experiences. Those interested were asked to give their contact details to the author, who sent them further information in the form of an information sheet and topic guide detailing the areas of enquiry. The topic guide, written as a series of questions under broad subject headings (Table 1), alerted respondents that the focus was firmly on death and dying, allowed them time to collect their thoughts before participating, and helped to ensure that verbal consent taken at the beginning of the interview was as fully informed as possible. Written consent to use the audio recording was obtained at the end of interviews.

TABLE ONE ABOUT HERE

Respondents were offered a choice of face-to-face interview, writing a letter or recording their experiences onto cassette, methods previously used to investigate the effects of illness on parents of

young people with cancer (Grinyer & Thomas, 2001). Those writing a letter or making a recording were asked to respond to the questions on the topic guide sent with the invitation letter. All respondents were assured that they did not have to answer questions they preferred not to, and that they were welcome to share information they thought relevant but had not been covered by the topic guide. All interviewees were told that they could stop the interview whenever they wished; although recording was stopped at points to allow participants time to mourn, all requested that they complete the interview. King's College London Research Ethics Committee granted ethical approval of the study. All participants were assured that their responses would be confidential and anonymised through use of pseudonyms.

Due to the method of posting the initial letters, it is not known how many letters sent by the CF Trust reached their destination. Many parents sever links both with CF services and other families affected by CF after their child's death; others move house (perhaps signifying the meaning and value of 'home') and some separate. Seventy-one people out of the 275 contacted requested further information. Two of these (both mothers) spoke at length to the author by telephone but did not want their stories included in the study. Both expressed dissatisfaction with their child's end-of-life care. Thirty-four individuals (32 of them parents) from 25 families located in Scotland, Wales and England participated during October 2003–March 2005, reporting 30 deaths of children from CF. No partners participated. Seven people wrote letters ranging from 1000 to 12,500 words; 26 people were interviewed either with a spouse or individually; and one sent a cassette (Table 2).

TABLE TWO ABOUT HERE

Due to the genetic basis of the disease, some families reported deaths of more than one child with CF. Three parents narrated the deaths of two children and one couple recounted the deaths of all

three children. Three of these children, aged 14 or under, died before 1994 and were not included in the analysis. Two families had another child living with the condition at the time of participation.

Analysis

All material was transcribed verbatim and checked against the original source (audio recording or letter) for accuracy. All data were imported into ATLAS-ti, the software package for qualitative analysis. Codes were assigned to words, phrases, paragraphs or sentences to assist with detection of themes and patterns (Miles & Huberman, 1994). Codes for place of death were assigned to home or locations within the hospital, and factors that appeared to influence positive and negative experiences of care were considered. During coding all respondents' transcripts were reread to ensure capture of how parents' reports of earlier experiences of care impinged on the meanings they attributed to the final place of care and death. Second order coding was used to identify recurrent themes and patterns, and to further understand reasons for negative cases.

Parents' accounts of deaths from 1999 to 2003 are reported for 27 adults with CF aged 17–36 years. The median age of death for men was 26 years and 22 years for women. Six young people were reported to have died at home and 21 in hospital. Although variability of the disease makes classifying 'unexpected' deaths difficult, respondents' accounts ranged from sudden deaths to health decline over a prolonged period, with eight young people reported to have refused to consider lung transplantation, or to have taken too long to make their decision when possibility of the intervention was first raised. In considering parents' meanings of place of death, findings are organised by the three aspects of 'place'; the built, social, and psychological environments.

Findings

The built environment

Twenty-one hospital deaths were reported; locations included specialist CF or transplant centres, local and district general hospitals. Twenty young people died whilst admitted for an episode of acute illness and one whilst being assessed for transplant suitability. Six died in ITU, one in the infectious diseases unit (IDU, used to protect young people from infection), one on a CF unit, and the remainder on hospital wards. Parents reported hospitals' variable provisions for family members during young people's admissions, from put-up beds to separate accommodation, with parents tending to report staying only for critically ill offspring. Parents reported being present for all but three young people's deaths, two of whom died on a ward and one in IDU. These 'absent' parents reported engagement with hospital environments across the disease course, and good care for their offspring at a point that they had not anticipated as becoming their place of death. Two families' absence was due to needing to fulfill home responsibilities, coupled with a long distance to hospital prohibiting speedy return, whilst for the other, absence was due to the unexpected and extremely sudden nature of death:

I said [to Tom], "Do you want me to come up and stay [at the hospital]?"...And he said, "That'd be lovely, Mum." So I made all the arrangements, this was on the Sunday...I phoned up on the Monday morning and said, "What sort of night has Tom had?" and they said, "Oh, all right." Half an hour later, the phone went and it was Sister and she said, "Rita, you'll have to come, but don't hurry, he's gone." [Tom's mother, interview, ward death]

Through a long period of care enabling parents' familiarity with the hospital built environment and medical technologies housed within, a clear engagement with the built environment was reported by five out of six parents who experienced their child's death in ITU. Parents who reported a home death were similarly engaged. However, two out of 13 families reporting hospital ward deaths recounted

problems arising from their having little control over the layout of the built environment and limited opportunity to leave the bedside:

It was horrendous! Absolutely horrendous! Because there was her bed like that [indicates with hands], and at the end of the bed was a full-length mirror and a clock. And she was just watching – she was watching herself die, and looking at the time. And I can tell you the exact minute she could die. We all did. Because we knew. Because that clock was there... And I can just – it was horrible, because you're watching the clock. [Dawn's mother, interview, ward death]

Despite being in a single room, a lack of privacy in the ward environment resulted from the arrangement of fixed items and parents' reported inability to move to a private space when attempting to talk to relatives about the dying young person:

I always thought if only they could have covered it [the payphone]. What a simple thing! Even if it wasn't really soundproofed, it would be a little bit of privacy for parents to sit and talk. Because also Edward was in room four, which was dead opposite [the payphone]. And very often a door would be open. And if I was trying to talk to [family members] about him or his condition, it's so difficult! I mean, how could I actually say to them, “He's so ill. Will you come?” [Edward's mother, interview, ward death]

In thinking of whether a particular built environment was preferred as a place of death, both Andrew's mother, who recounted unsuccessful resuscitation attempts following Andrew's collapse at the specialist centre where he was being assessed for lung transplant, and the mother of Adam, who died unexpectedly at home using non-invasive ventilation whilst waiting for transplant, reported that they believed the actual place of death to have been the ‘best’ one for their sons:

[Author]: Would you have rather Andrew had died at home? I mean, if he got to the point where –
?

Mother: [sighs] No, I don't think I would, because I think then I would have been asking myself, “Now, would it have been different if he'd been in hospital?” [Andrew's mother, interview, CF unit death]

However, although both sons had opted for a lung transplant ‘pathway’ where a range of aggressive treatments delivered both at home and in hospital are the norm, Adam's mother intimated that to be taken to hospital would have led to his receiving futile resuscitative treatment, which would only have prolonged his dying:

I was so lucky the CF nurse was there [on a routine visit at home]. Because if I'd come home and found Adam like that [semi-conscious] – because he might have been like that – and if he would have kept going, once I'd sort of screamed a bit, I suppose I would have called an ambulance, because I don't, I wouldn't really know what else to do. And he would have gone to hospital! Oh God! Can you imagine? [Adam's mother, interview, home death]

In each participant's account, the built environment can be seen as a proxy for parents for the choice of treatment pathway, and the availability of care. ‘Place’ in this context determined for parents both availability of technological interventions and staff at end-of-life, mediated by the speed of offspring's health decline, the social organisation and delivery of care, and families' relationships with staff. It is to these issues of the social environment that we now turn.

The social environment

Determining location of death through rate of health decline

Evident throughout accounts was how the speed of health deterioration influenced treatment options available. Only one young person was reported to have undergone cardio-pulmonary resuscitation following collapse, which was unfortunately unsuccessful. This extremely rapid, unexpected health deterioration and sudden death occurred whilst Andrew was admitted for transplant assessment and aggressive care which attempted to improve both the quantity and quality of his life. In contrast, a relatively slow rate of health decline enabled other young people, their family, and a range of hospital and community services to plan for structured, supportive end-of-life care to be delivered at an agreed location, although this was not necessarily home. For example, Jude had reportedly refused transplant assessment and had parents experienced and competent in delivering CF care being supported by CF and community teams. However, he was reported to not want to leave the hospital to die at home; his engagement with the ward environment appeared at odds with what his parents had anticipated, and suggested the primacy of his safety and security within the ward, perhaps through engagement with familiar trusted staff, or through not wishing to be a burden on family members:

I said, “Well, we won't say anything to Jude about bringing him home until we find out whether or not we can get any sort of support.” So [the CF team] spent a couple of days – I think they liaised with the GP, and they'd said, “... the Macmillan nurses will provide a sitter two nights a week so obviously the pair of you [Jude's parents] can get some sleep. And your GP's prepared to do whatever.” I suppose see to the morphine and stuff like that, I'm not sure exactly what would have been involved. We were all quite au fait with the syringes and drawing up the drugs and all that, so it wasn't going to be a problem... When we knew that we could do it, I said to Jude, “Do you want to go home then?” And he said, “No, I think I'll stay in hospital, Mum,” because he said that the nurses

are more au fait with everything and, “I forgot to have my medication changed and it might be a bit difficult.” [Jude's mother, interview, ward death]

In contrast, although Nathan had also decided against lung transplantation assessment and aggressive intervention, he and his family were able to initiate plans for an end-of-life care ‘pathway’ that enabled him to die in the family home environment, which involved inputs from the CF nurse specialist, hospice and district nursing teams. Planning a home death could also occur at a relatively late stage in the transplant ‘pathway’. For example, following admission to the transplant centre for surgery, where donor lungs were found to be damaged and therefore unusable, one young woman had requested to be taken off the transplant list. Tamsin, living with her husband at her parents' home, was able to plan a home death after the CF team gave a clear signal that her care pathway had then changed from active to palliative, and discussed options with her family:

Basically, [the CF team] said, “Well, we know she hasn't got very long. It might only be a matter of days. And what she really wants is to be at home.” And we said, “Yes, that's fine.”...She came home, and [her husband] had compassionate leave from work, and we nursed her at home. [Tamsin's father, interview, home death]

Evident in these accounts of health decline is the organisation and coordination of a range of services that are required to respond to a change in health status in both the hospital and home environments. In the following section, how social organisation of this care and interactions with staff influenced experiences of end-of-life care are considered.

Organisation and delivery of care

The concept of opposing pathways of refusing transplant or opting for aggressive treatment is vital in understanding current organisation and delivery of end-of-life care for those with CF. Usually, these pathway choices imply an opportunity to discuss potential place of dying relatively early in the disease course. However, five young people, reported not to have wanted transplant assessment, had not expressed to their parents a wish to die at home. For three of these, parents subsequently perceived the hospital ward as a place of safety for them, due to the availability of familiar staff and palliative interventions. However, for the other two young people who had refused transplant assessment and had died on hospital wards, absence of supportive organised care led respondents to recount a bad end-of-life experience. For example, Kenny's mother had reported ward doctors' care of her other son with CF at end-of-life as “absolutely marvelous”, but remained extremely distressed by her experience of Kenny's death:

By the time the nurse came in – who we didn't know – she said, “Oh, he's dead.” Well, I felt like swearing at her. And I said: “We know he's dead.” Well, she went! She went! And we were half getting him [back] on the bed, and one of the nurses just came in and took his injection, his needle out from his stomach, and we were trying to get him on his bed...No-one came in and oh, it was dreadful! It was just dreadful. Really, really dreadful. I would not let, I would not let – I mean I love animals, and I wouldn't let an animal die like that! [Kenny's mother, interview, ward death]

Five families reported six young people to have died in the ITU whilst receiving aggressive treatment. All, having opted for transplantation, were using mechanical ventilation, which ultimately determined their place of death. Mark, awaiting assessment for transplantation, was using non-invasive ventilation; the remainder were intubated. Two of the five intubated died

whilst waiting for donor organs, and three had received a transplant. The suddenness of death following withdrawal of invasive ventilation for these five meant that it was inappropriate to consider another location of care once the outcome was considered terminal.

Established and valued relationships with CF teams had been built through patients' and families' long period of contact with them. Parents of the five intubated young people who died in ITU appeared engaged through shared decision-making about care, privacy, and a peaceful death. These deaths were reported to have been very sensitively managed by CF teams, who discussed care preferences with families and sensitively managed advanced technologies in an attempt to balance hope for those waiting for donor organs with acknowledgment that an end-stage had been reached:

I was advised on the Sunday morning to consider taking her off the life support as the infection was not responding to the huge amounts of antibiotics and the scarring on the lungs had caused the lungs to harden/stiffen. By Sunday afternoon her kidneys had failed and I was informed that if I did bring her round she may have suffered brain damage. I could not let her suffer ANYMORE; she deserved so much more than this. I decided to let her go peacefully in my arms, on our own. It was only an hour at the most from the time that all of the medications other than morphine and ventilation were stopped, that she passed away. [Diana's mother, letter, ITU death]

However, one parent did not perceive such good care to have been delivered at end-of-life in ITU. This was not due to staff's poor care, but rather frustration over local hospital policy restricting the use of non-invasive ventilation to high dependency areas, although parents at other hospitals reported offspring using this technology in both ward and home environments.

Here, location of end-of-life care was intimately bound to local hospital policy and the dependency on advanced technology in supporting both living and dying:

Mark had reached the stage that, although he could converse, and was still bright, he could not breathe for more than a short while without a BiPAP [non-invasive ventilation] machine. [The hospital] have regulations forbidding use of BiPAP outside the Intensive Care and High Dependency units. These regulations are just local bureaucracy...He would have been happier to end his days with the Isolation team. We appreciate that the hospital takes steps to avoid being sued for inadequate care. However, over 24 h before he died, they wanted him to unblock the bed by returning him to isolation with no BiPAP. That would have been death within minutes, which we all objected to whilst there was the slightest chance of a transplant. Also, the death would have been painful struggling for the last breath without assistance. [Mark's father, letter, ITU death]

A generally high standard of end-of-life care organised and delivered without the use of advanced technology was also apparent in more 'low tech' hospital deaths outside the ITU. Although Dean's parents had not been able to reach hospital in time, they reported being reassured by the presence of a familiar nurse:

Dean's Father: We met all of the nurses and we knew all the team. And [the nurse] even said, "I gave him a cuddle" you know.

Mother: By all accounts, he just, she sat at the side of him, and he wasn't laying down – he couldn't bear to lay down. And she said, "I put my arms around him." And she said, "Come on, love, put your head on my shoulder." And she said, "I realised that he was going. But I

couldn't leave him and go and get the phone and ring you.” And she pressed the [call] button to let the night nurse know that this was what was happening. [Dean's parents, interview, IDU death]

Rarely, bad experiences of end-of-life care, predominantly experienced through ward-based deaths, were reported by parents and were attributed to a lack of relational continuity of care: satisfactory relationships with certain CF team members had not been established; key members of the CF team were not available for consultation; or unfamiliar staff were perceived to be untrained and uncaring. For one mother, nurses calling in specialist palliative care staff only at the very end of her daughter's life demonstrated an ill-timed coordination of services that did not allow for establishment of personal relationships:

I was really annoyed, because about two hours before she died, [the nurses] called me outside and said, “Look, we've got the palliative care nurse here,” – who I'd never, ever clapped eyes on before – “would you like her to come and sit with you?” And I think I snapped, “No, thank you! I'm quite alright!” Because I didn't want a stranger there. [Dawn's mother, interview, ward death]

In summary, rate of health decline, organisation and delivery of care, and relationships with staff were key factors of the social environment that determined how an offspring's death was experienced by parents. These were mediated by, but not dependent on, physical location. Briefly, we consider to what extent parents reported taking meaning from place of death.

The psychological environment

Parents believed that their offspring perceived locations in the hospital environment to be both places of threat and safety throughout their lifecourse, through admissions signifying an increased risk of death, yet offering ‘rescue’ therapy, familiarity and comfort at points of acute illness. Ambiguity surrounding the meaning of hospital admission was compounded by the array of home-based technologies that was available to young people, which they were reported to use in attempts to delay hospital admission. This ongoing ambiguity may have contributed to young people's reported inability to choose and express clearly a preferred place of death.

Through their years of hospital appointments and admissions the vast majority of parents reported their children knowing other young people who had died from CF. Symbolic meaning was taken from the physical environment through memories of these others' deaths, which some parents reported to influence their child's albeit restricted choice of place of death, especially within a ward environment experiencing a high number of CF admissions:

The doctor said to me, “He should be in a room on his own,” because there's like a ward full of people there and Kenny was a spectacle really...I said that he won't go in the room that they've offered him, because his friend died in there a couple of months ago, and he won't, he just feels awkward, because he doesn't want to go in that room.
[Kenny's mother, interview, ward death]

However, focusing on place of death per se appeared to be of far less importance to parents than focusing on factors that influenced positively experiences of care at end-of-

life. Indeed, place as a physical environment may be irrelevant to some parents and their dying relative:

Did Mark die where we would have wished? We would have preferred him not to die. However, we held his hand for the last 48 h and the location is of minor importance.
[Mark's father, letter, ITU death]

It appears from parents' accounts that it is the availability of advanced technology to support the choice of aggressive care or refusal of transplant, and familiar, trusted staff available to young people and their family at the time of death that are of paramount importance to families in determining and giving meaning to place of death. Nadia's mother summed up this belief in the context of her daughter's death which she reported with great upset; familiar CF team members had been absent and hospital nurses were reported as being uncaring and uncommunicative both before and after Nadia's death:

But it doesn't matter if you're in a bed in the middle of nowhere; if you're getting love, attention and care, it doesn't matter where you die, really, as long as the way you die is done with dignity. [Nadia's mother, interview, ward death]

Discussion

Considering meanings of the place of end-of-life care and death of young adults with a life-limiting condition is complex where the disease course is variable and uncertain, and aggressive and palliative treatments are often administered in tandem until death. The rapid health decline of many young people occurs against a background of significant improvement in this population's survival age, fuelling tensions between attempts to extend lifespan through use of advanced technology and

enabling young adults to die within a more traditional palliative care model. Within the physical boundaries set for the use of advanced technology such as mechanical ventilation, social, policy and symbolic contexts mediated parents' engagement with, or estrangement from, place, both at home and within hospital environments. In each location, family involvement in treatment decision-making with familiar and trusted staff was pivotal in parents' evaluation of end-of-life care for their children, although no physical location appeared to be the 'best' place of care or death for this population.

Retrospective accounts from parents affected by the death of at least one child with CF have been presented. Although this small group is perhaps not representative, a wide range of final cause and location of death were reported from families who in total had accessed over 70 British healthcare services providing a wide range of CF-related treatment across their children's lifespan, with reported location and age at death similar to other recent studies (Dellon et al., 2007 and Ford and Flume, 2007). All young people had at least one parent caring for them within a supportive social environment, with most parents reporting periods of engagement and estrangement with care over the young person's lifetime. Only parents' views are represented here; it is likely that young people and CF team members may express different opinions of care required and provided.

Problems with using retrospective data include recall and subsequent events influencing perception of past events, such as the resolution of a complaint about hospital care. However, issues raised by parents concerning other children currently living with the disease were similar to those discussed for the deceased child. For example, difficulties surrounding advanced treatment decision-making due to uncertainty of the disease process suggest that although national policy now focuses more on end-of-life care for those with non-malignant disease (Department of Health, 2008), this will take time to impact on 'new' ageing populations with life-limiting conditions where striving for improvement in survival age remains key.

The narrative accounts gained though respondents' letters have weaknesses; not all accounts suggested the choices offered to young people or their parents, offered reasons for decisions made by individuals, or explicitly expressed a preference for place of death or end-of-life care. However, this approach to data collection put minimal pressure to participate on families, whose experiences at end-of-life are usually lost to health services, policy makers and researchers. It also allowed people to write their story in their own time and pace and perhaps upheld families' desire not to meet with a stranger (Grinyer, 2002). It is likely therefore that concepts generated here serve to illuminate some of the complexities of providing end-of life care to young people who still do not survive mid-life (Dodge et al., 2007).

It has been suggested that 'place' is a proxy measure of the quality of end-of-life care (Exley and Allen, 2007 and Gott et al., 2004); the physical location being of less importance than the social and emotional relationships housed within (Exley & Allen, 2007). Here for example, although ITU cannot emulate the physical characteristics of 'home' in terms of furnishings and artifacts, it has been demonstrated that a 'good' death in this high-tech environment is achievable, based on families' relationships with familiar supportive and trusted staff, and their felt inclusion in decision-making. Conversely, despite the comfort and privacy that single rooms in ward environments might offer, it is the general ward environment that appears less likely to offer a 'good' death, through staff reported to be unfamiliar with both the young person and the specialist care required.

This study demonstrates that it is the use of more advanced technologies at end-of-life, housed in a range of locations within acute hospital environments that is an additional important proxy measure of the quality of end-of-life care for this population. Here, location of death was often limited by young people's rate of health decline and their choice of aggressive treatment. Notions of aggressive

care and end-of-life care are therefore intertwined for those affected by CF, with place of death being influenced by the two care pathways. Advanced technologies usually determined place of end-of-life care and death within the ITU or high dependency environment, thus limiting families' preference and capacity to provide care at home. Policy for a 'good' death must therefore take into account the use of advanced and evolving technological interventions within each space and the potential for its restriction or portability to alternative settings.

However, home and hospital ward environments continue to become more fluid for these 'new' ageing populations through the movement of more 'simple' routine technologies such as intravenous drug equipment into the home setting (Poland et al., 2005). Through routine home care provided throughout the lifespan, home space for this population may already be considered as a quasi-clinical context. Furthermore, frequent hospital admission and regular invasive therapy can ensure long and trusted relationships with professionals within the hospital environment, which then has the potential to become a 'home-from-home' for those dependent on medical interventions throughout life.

'Home' cannot therefore be the sole policy focus for defining the 'best' place of death for this highly medicalised, technology-dependent population, used to receiving treatment and care across a variety of familiar built environments. If professionals understand and respond to these factors that families deem important, then a 'good' death can occur in places outside the home (Grinyer & Thomas, 2004).

An end-of-life care strategy must therefore focus both on specific locations within the built environment of 'acute hospital' care (Department of Health, 2008) and home, and the technological, social, and psychological processes found therein. Attempts to increase the proportion of home deaths for 'new' ageing populations such as those with CF are likely to be misguided if these elements are not addressed. As more people with life-threatening conditions live lives dependent on

advanced technology, further research into how place and technology impact on care at end of life is urgently required.

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Table One: Abridged topic guide showing broad subject headings

Events leading up to relative's death

Discussions between young person, staff and family about dying and death

Consideration of organ transplantation

Place of care at end of life

Place of death

Family's bereavement experiences and support

Table Two. Participants recounting end-of-life care and death of a young adult with cystic fibrosis

Name	Age at death	Place of death	Respondents replying by letter (L), interview (I), or cassette (C)
Diana	17	Hospital (ITU)	Mother (L)
Nadia	19	Hospital ward	Mother (IV)
Tamsin	20	Home	Mother & Father (joint IV)
Jude	20	Hospital ward	Mother (IV)
Clarissa	20	Hospital (ITU)	Mother & Father (joint IV)
Tamara	21	Home	Mother (IV)
Dawn	21	Hospital ward	Mother (IV)
Andrew	22	Hospital (CF unit)	Mother (IV)
Samuel	22	Hospital (ITU)	Mother (L)
Adam	22	Home	Mother (IV)
Edward	22	Hospital ward	Mother (IV)
Fergus	23	Hospital ward	Mother & Father (joint IV)
Dean	24	Hospital (IDU)	Mother & Father (joint IV)
Glenn	28	Home	Mother (L)
Lewis	30	Hospital ward	Mother (IV); Sister (L)
Julia	31	Home	Mother (IV)
Nathan	31	Home	Mother & Father (joint IV)
Sid	33	Hospital ward	Mother (L); Father (L)
Mark	33	Hospital (ITU)	Father (L)
Damien	36	Hospital ward	Mother (IV); Sister (IV)
Tom	36	Hospital ward	Mother (IV)
<i>Siblings:</i>			
Nicholas	10 weeks	<i>Outside study period</i>	Mother & Father (joint IV)
Susan	13	<i>Outside study period</i>	
Francesca	29	Hospital (transplant ward)	
<i>Siblings:</i>			
Laura	14	<i>Outside study period</i>	Father (IV)
Justin	17	Hospital ward	
<i>Siblings:</i>			
Kendra	19	Hospital (ITU)	Mother (IV)
Chantelle	21	Hospital (ITU)	
<i>Siblings:</i>			
Martin	24	Hospital ward	Mother (IV)
Kenny	32	Hospital ward	